
Stores of Hope: Huntington's Disease



Sherry lives balanced on the odds of a coin toss.

Since she was 9, when her father was diagnosed with Huntington's disease, she's known that she has a 50-50 chance of receiving the same diagnosis. During the next decade, as she watched her father fail tragically, his personality changing, his body growing weaker, she coped by staying busy, swimming and playing water polo.

Just knowing she might develop Huntington's is a malady. So many things worry her. "If I trip or fall or mess up at work, I think, 'Oh, I might have HD.' If I'm moody or something, I wonder, 'Is this like the first sign?'"

That's one reason Sherry hasn't taken the genetic test to learn her status. "If I tested positive, I would symptom search even more than I do now."

Another complication: She doesn't give her last name because she fears discrimination that could follow if her risk status were revealed.

She worries even more about losing the abilities that matter to her. "I love outdoor activities. I love traveling, reading, talking, walking, eating—I'm very good at eating. I just don't want to give up those things I love most in life: my relationships, my independence."

Still she is optimistic about stem cell research. "Whenever I'm having a rough day, I think about it. It just gives me hope."

- Watch the Spotlight on Huntington's Disease talks
- Read more about CIRM funding for Huntington's disease research

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